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Supportive Care in Cancer

What do radiation therapists know about health literacy and the strategies to improve it for patients? A qualitative study.

--Manuscript Draft--

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Abstract:	<p>Purpose Low health literacy leads to poor knowledge and understanding of health information, delayed diagnosis, lower use of preventative medicines/health services, increased likelihood of hospitalisation, and increased patient anxiety. Effective communication facilitates patient understanding and helps patients to manage the adverse side-effects associated with treatment. It is not yet known whether radiation therapists in Ireland tailor their communication to match a patient's health literacy level. The purpose of this research was to investigate radiation therapists' knowledge and awareness of health literacy and perceptions of their role in supporting patients with low health literacy.</p> <p>Methods Semi-structured interviews were conducted with sixteen radiation therapists working in four radiotherapy departments in Ireland. Data were analysed using the Framework approach.</p> <p>Results Through discussions with participants it was apparent that radiation therapists had limited knowledge of the concept of health literacy. Common themes arose from the interviews with four key themes identified: 1.Strategies used to identify patients' health literacy 2.Perceived effect of low health literacy 3.Obstacles faced when addressing low health literacy 4.Recommendations to support lower health literacy groups</p> <p>Conclusion Currently, radiation therapists show some knowledge and awareness of health literacy but an increased awareness of the prevalence of low health literacy and a structured</p>

	approach to supporting patients would allow radiation therapists to more effectively communicate with patients, thus improving their treatment experience and reducing the risk of adverse outcomes.
Response to Reviewers:	please see attachment "replies for reviewers"

Response to reviewers comments

Reviewer #1

1. Firstly, congratulations on an interesting study that warrants publishing. Overall it is well written and most RTs would be able to relate to what you discuss. The recommendations below are minor.

Thank you for your encouraging comments on the manuscript.

2. Introduction: You mention the three subtypes of LHL as highlighted by Nutbeam. Briefly expand on these as they are a key part of your manuscript.

Thank you for this suggestion. The 3 different types of health literacy are now presented in Table 1, page 3.

3. Methodology: With the analysis mention why only one researcher looked at the data it is common place for two researchers to independently explore data with qualitative research to help with the validity and reliability of the results. You touch on this in the limitations however explain the rationale behind this in the methodology.

Thank you for raising this important point about the analysis. We agree that it is common place for two or more researchers to independently code qualitative data, and then discuss their coding and interpretations of the data.

To enhance the credibility and integrity of the analysis and results, we decided to go back and reanalyse the interview data with 3 of the co-authors. The re-analysis was an iterative, rigorous process involving the co-authors independently coding around 50% of the interviews using the coding framework and then comparing and contrasting interpretations and results from the Australian study.

What would have you done if your research had different results to the Australian study?
How did you ensure you were not led by the Australian study to get the same results?

With regard to the results not being led by the Australian study, the current analysis was both inductive and deductive. That is, it began deductively using a priori questions drawn from the key aims of the research and shaped by the interview schedule (which was an adapted version of the Australian interview schedule). The themes were identified inductively by maintaining close links to the original data and ensuring that our interpretations of the data were fully supported by participant quotes.

During the re-analysis, we focused on comparing and contrasting the Australian and Irish study, and reporting more on the similarities and differences between the two different country/study contexts.

We have added the following text additions to address the points made above in the introduction and methods section:

Introduction, Page 3: *Due to the dearth of studies on HL in radiation oncology in Ireland, we aimed to build on the Australian research by exploring whether radiation therapists working in Ireland address HL in their clinical practice. Specifically, the present study aimed to explore in an Irish population: (i) RT's knowledge and awareness of health literacy; (ii) RT's perspectives on how to care for and support people with LHL; and, (iii) the specific barriers and facilitators to doing so. Results from the current study were then compared and contrasted with findings from the Australian study to explore similarities and differences in how RT's address HL difficulties in the two different countries.*

Methods, page 4: *Author, FQ led the data analysis, and 3 authors (AC, SS, HD) independently coded 50% of the transcripts, then discussed the issues identified in the data and any discrepancies in coding.*

4. Results and Tables: You have a lot of quotes in your tables that are almost distracting. Choose two good quotes for each point - you have enough data there for this to have an impact. Similarly in the results section you could direct readers to the quotes in the tables (the are well numbered) or just choose some good quotes that illustrate what you are saying in each section. Then you might evaluate if you need the tables at all?

We agree that the amount of quotes was rather distracting. As suggested, we have reduced the number of quotes that support each point in the tables. We have now combined tables 3 & 4 into one table (this is now labelled as Table 4).

5. Discussion; In this section don't repeat what you have already said in the results section some of the discussion is repetitive of the results section and consequently quite long. Look at both sections together and avoid the repetitive statements. Some of the summaries you have used in the results section could be used in the discussion instead of the results. Use subheadings too which will help the flow of this section.

We have edited the discussion to avoid repetition and integrated some summaries from the results into the discussion of the results (see pages 6-7).

If permitted by the journal, we would be happy to include sub-headings in the discussion section.

Reviewer #2 comments

1. Your title really doesn't capture the main thrust of your work. It makes the reader believe that the focus is solely on the RT and how a deficit in health literacy knowledge of the RT can be made, when in fact much of the study relates to the patient as an important focus - consider re-wording your title to better reflect the aims i) ii) and iii) that you lay out in your introduction.

Thank you for this suggestion on re-wording the title to reflect the key aims. We have reworded the title to, '*What do radiation therapists know about health literacy and the strategies to improve it for patients? A qualitative study*'.

2. When introducing your project, instead of stating that it wishes to build on the Australian study could you be more clear about what specifically you are adding to the literature with your project? What knowledge gaps remain unfilled following the Australian study that you wish to fill?

We have added the following text in the introduction to specify what our project aims to add to the literature.

Level of HL across OECD countries vary substantially and diversity within country populations may account for some of this variation. For example, Australia is a multi-cultural society with cultural and linguist diversity a core element of the population. Around 25% of the Australian population were born overseas, and 60% are described as having limited HL skills to read and understand basic health information [8]. By comparison, Ireland has limited cultural diversity and 40% are described as have limited HL skills [6].

Due to the dearth of studies on HL in radiation oncology in Ireland, we aimed to build on the Australian research by exploring whether radiation therapists working in Ireland address HL in their clinical practice. Specifically, the present study aimed to explore in an Irish population: (i) RT's knowledge and awareness of health literacy; (ii) RT's perspectives on how to care for and support people with LHL; and, (iii) the specific barriers and facilitators to doing so. Results from the current study were then compared and contrasted with findings from the Australian study to explore similarities and differences in how RT's address HL difficulties in the two different countries.

3. What were your hypotheses?

Given the qualitative nature of the study and the fact this is a relatively new area of enquiry, the current study set out to explore radiation therapist's understandings of health literacy rather than test hypotheses (predictions that require statistical tests).

4. What kind of denominator are we talking about here - how many centres and how many RTs are there in Ireland?

We include this information now in the methods:

RTs from the 12 radiation oncology hospitals departments in the Republic of Ireland were invited to participate.

From approximately 200 radiation therapists working in Ireland at the time of the study, 16 RTs consented and participated.

5. Having the managers suggest RTs to interview introduces selection bias - please comment on potential challenges with this within the Discussion

We apologise for the confusion and wish to clarify that managers did not recruit RTs to the study. The text has been amended in the methods section:

Managers in each department were contacted and asked to nominate a member of clerical staff to liaise with the researchers in distributing study details to eligible staff.

6. Were participants paid for their time?

No, participants were not paid/ reimbursed for their time. We have amended the text as follows.

Following this, timeframes for obtaining informed consent and conducting interviews were arranged with the volunteer RT.

7. Did the person doing interviews travel to all the centres, or were face-to-face interviews done electronically over Facetime or Skype or some platform like that? If yes, any potential challenges that you foresee?

All interviews were conducted face-to-face. This is now clarified in the text.

Interviews were conducted face-to-face by researcher, FQ, who travelled to each site to interview participants in person.

8. Tell us how you adapted the Australian interview schedule please - what were the modifications and why were they made? Again, make a case for why we should read your article and not just fetch the Australian one. Providing some amount of material from the interview guide in the main body of text would be helpful rather than just the supplementary material - prioritize your tables and data here. All your results and conclusions rely on the structure of the interview guide so this seems like something that should be provided here.

The following text was added to identify the modifications that were made to the schedule used in the Australian study.

The interview schedule broadly covered how HL is assessed, adjustments made for LHL patients, and barriers to supporting this patient group. An example of questions included: 'Could you characterise a typical low HL patient?', 'Do you interact with, or do anything differently in your approach with low literacy patients?', and 'Do you feel

there are barriers or obstacles to helping this type of patient?’ This schedule was adapted from the Australian study mentioned previously [14]. Modifications included changes to match local terminology such as “first day chat”. Questions seeking participant views on screening for HL level, informed consent, and recording of information sessions were also added.

9. Analysis done by only one researcher here is a weakness of the study. Can you go back and have a parallel analysis with a second independent reviewer? This is fairly commonplace for these types of studies. Were more than one person at least involved in creating the coding framework? A very strong case for why only one person analyzed would need to be made here for the article to warrant publication.

Thank you for raising this important point about the analysis. Reviewer #1 also raised this point (response 3 above). We agree that it is common place for two or more researchers to independently code qualitative data, and then discuss their coding and interpretations of the data.

To enhance the credibility and integrity of the analysis and results, we decided to go back and reanalyse the interview data with 3 of the co-authors. The re-analysis was an iterative, rigorous process involving the co-authors independently coding around 50% of the interviews using the coding framework and then comparing and contrasting interpretations and results from the Australian study.

During the re-analysis, we focused on comparing and contrasting the Australian and Irish study, and reporting more on the similarities and differences between the two different country/study contexts.

We have added the following text additions to address the points made above in the introduction and methods section:

Due to the dearth of studies on HL in radiation oncology in Ireland, we aimed to build on the Australian research by exploring whether radiation therapists working in Ireland address HL in their clinical practice. Specifically, the present study aimed to explore in an Irish population: (i) RT’s knowledge and awareness of health literacy; (ii) RT’s perspectives on how to care for and support people with LHL; and, (iii) the specific barriers and facilitators to doing so. Results from the current study were then compared and contrasted with findings from the Australian study to explore similarities and differences in how RT’s address HL difficulties in the two different countries.

Author, FQ led the data analysis, and 3 authors (AC, SS, HD) independently coded 50% of the transcripts, then discussed the issues identified in the data and any discrepancies in coding.

10. Were there other systems of analysis that you considered besides those listed in refs 16 and 17? Could you state why your chosen system was the best for this study? Data were analysed thematically using the Framework approach, a matrix based method for managing, analysing and interpreting qualitative data. This is a very common method of

qualitative analysis used in health and medical research. It was chosen because ‘Framework’ method is a rigorous and iterative process involving five distinct steps whereby researchers repeatedly move back and forth between the different phases of analysis. Framework is also useful for comparing and contrasting participants’ responses as every participant is assigned a row, while each subtheme is allocated a separate column.

11. How did you determine your sample size?

As the study design is qualitative, the number of participants recruited was guided by data saturation. That is, recruitment to the study continued until the authors determined that thematic saturation had been achieved as indicated by data redundancy – that is, when participants no longer raised themes or issue not already elicited in earlier interviews.

12. Was this study funded by an external source?

This study was not funded by an external source. This study was carried out as part of a four year honours undergraduate programme, BSc (Radiation Therapy).

13. All participants were female. Any potential bias in results because of this?

Thank you for observing this. We have added the following text in the methods and discussion to highlight this point.

Representative of the predominantly female RT profession in Ireland, all were female, with ages ranging from 22 to 54 years.

Secondly, although representative of the largely female dominated profession in Ireland, these results may not be applicable to male RTs.

14. How do your major identified themes differ from those of the Australian study? There is no mention in the results about how your study compares and given that you build the introduction by saying you're expanding on that study I expected to see a comparison.

Thank you for highlighting this point. In the discussion, we compare and contrast the Irish study to the Australian study, for example...

This study details RTs in Ireland’s knowledge and awareness of HL and the strategies used to enhance the care and support of patients with LHL adding to the limited studies of HL in radiation oncology by building on a previous Australian study. Similar results to the Australian study emerged with, our results also indicating RTs make subjective, intuitive judgements of patients’ HL level at initial interaction and throughout their treatment, and use numerous methods to identify patient HL level. Adding to the Australian results, we identified acceptance of consultation recording as an intervention for consideration, current issues with LHL and consent, and concern with future screening for HL.

15. You discuss how RTs had a facility with the functional element of literacy but not communicative or critical. I don't think you've actually told us what the differences are anywhere though. Sorry if I've missed it, but if not, I suggest you show us if you're going to report results as a function of the 3 elements.

This was also highlighted by reviewer #1 (point 1). The three different types of health literacy are now presented in Table 1.

16. What are your next steps with this data now?

The following text has been added to the discussion to inform the reader of the next steps:

Communication skills training can help address the lack of awareness and equip health care professionals with skills necessary to effectively support and care for this patient group [36]. Although further evidence of feasibility and benefits of training is needed, the undergraduate programme for Radiation Therapist's in Ireland has been updated to include lectures on HL, and wider dissemination to the Radiation Oncology professional community has occurred via oral presentations at national conferences. Studies exploring interventions to enhance communication skills in RTs [37] or providing tools to support communication with patients in radiation oncology have shown promising results [38], but further effectiveness and implementation research is needed to bring these into standard clinical practice.

17. A very thin discussion of potential limitations - please use more space to comment on some of my points above.

As suggested, the limitations section has been expanded.

This study had some limitations. Firstly, the self-selection of participants, with volunteers likely to have an interest in the area. However, given the low awareness of the concept of HL, this did not seem to be the case. Secondly, although representative of the largely female dominated profession in Ireland, these results may not be applicable to male RTs. Thirdly, as this qualitative study includes interviews only with RTs, it is not possible to explore the implications of these data in the context of the multidisciplinary radiation therapy team. Lastly, as we relied on self-reported accounts rather than investigating what RTs say in consultations, this study may have a social desirability response bias, where RT's interactions with patients may be different to their account of these interactions.

18. Be careful not to just provide more results-type data in the discussion - reserve the space for reflection and in-depth explanations/questions.

We have edited the discussion to avoid repetition and by comparing and contrasting with the Australian study, we have provided more in depth explanation on some of the findings. (see pages 6-7).

[Click here to view linked References](#)

What do radiation therapists know about health literacy and the strategies to improve it for patients?

A qualitative study.

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What do radiation therapists know about health literacy and the strategies to improve it for patients?

A qualitative study.

Abstract:

Purpose: Low health literacy leads to poor knowledge and understanding of health information, delayed diagnosis, lower use of preventative medicines/health services, increased likelihood of hospitalisation, and increased patient anxiety. Effective communication facilitates patient understanding and helps patients to manage the adverse side-effects associated with treatment. It is not yet known whether radiation therapists in Ireland tailor their communication to match a patient's health literacy level. The purpose of this research was to investigate radiation therapists' knowledge and awareness of health literacy and perceptions of their role in supporting patients with low health literacy.

Methods: Semi-structured interviews were conducted with sixteen radiation therapists working in four radiotherapy departments in Ireland. Data were analysed using the Framework approach.

Results: Through discussions with participants it was apparent that radiation therapists had limited knowledge of the concept of health literacy. Common themes arose from the interviews with four key themes identified:

1. Strategies used to identify patients' health literacy
2. Perceived effect of low health literacy
3. Obstacles faced when addressing low health literacy
4. Recommendations to support lower health literacy groups

Conclusion: Currently, radiation therapists show some knowledge and awareness of health literacy but an increased awareness of the prevalence of low health literacy and a structured approach to supporting patients would allow radiation therapists to more effectively communicate with patients, thus improving their treatment experience and reducing the risk of adverse outcomes.

Keywords

Health literacy, radiation therapist, radiotherapy, patient education, cancer, qualitative research

What do radiation therapists know about health literacy and the strategies to improve it for patients? A qualitative study.

Introduction

When faced with a cancer diagnosis, patients are presented with information about their cancer, treatment, and possible outcomes. Most, especially those with low health literacy are likely to have difficulties understanding concepts and medical terms [1,2]. Health literacy (HL) is defined as ‘the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health’ [3], and comprises three subtypes: functional, communicative, and critical (Table 1)[4]. The European Health Literacy survey [6] investigated HL levels in the general population across eight EU states, found that 10% and 30% of Irish participants had inadequate or problematic HL levels respectively [7].

Level of HL across OECD countries vary substantially and diversity within country populations may account for some of this variation. For example, Australia is a multi-cultural society with cultural and linguist diversity a core element of the population. Around 25% of the Australian population were born overseas, and 60% are described as having limited HL skills to read and understand basic health information [8]. By comparison, Ireland has limited cultural diversity and 40% are described as have limited HL skills [6].

Low health literacy (LHL) leads to: difficulty understanding health information, poorer health knowledge, delayed diagnosis, lower use of preventative measures, increased likelihood of hospitalisation and patient anxiety, and limited ability to participate in decision-making [9, 10] . Due to the negative impact of LHL and the direct link between patient HL level and health outcomes [11,12], efforts must be made to identify and support the LHL population.

Radiation Therapists (RT’s) provide support and information on a daily basis to patients, and are ideally positioned to optimise communication. Whilst studies have assessed patients’ information needs, few have explored how RTs support and deliver information to LHL patients [13,14]. An Australian study found that radiation therapists appeared to use a number of cues to help identify patients considered to have LHL, such as language skills, body language, and question-asking [15]. For patients perceived to have LHL, radiation therapists reported using plain language with minimal medical terminology, photos, and analogies [15, 16].

Due to the dearth of studies on HL in radiation oncology in Ireland, we aimed to build on the Australian research by exploring whether radiation therapists working in Ireland address HL in their clinical practice. Specifically, the present study aimed to explore in an Irish population: (i) RT’s knowledge and awareness of health literacy; (ii) RT’s perspectives on how to care for and support people with LHL; and, (iii) the specific barriers and facilitators to doing so. Results from the current study were then compared and contrasted with findings from the Australian study to explore similarities and differences in how RT’s address HL difficulties in the two different countries.

Table 1 Health literacy levels [2].

Type	Definition
1. Functional health literacy	Basic reading comprehension and writing skills to understand health information/messages, together with knowledge of health conditions, services (e.g. treatment) and systems
2. Communicative/interactive health literacy	Higher level communicative and social skills required to extract and discuss health information with other
3. Critical health literacy	Advanced literacy, cognitive and social skills to analyze information and make informed health decisions

Methods

Study Design

A qualitative approach was taken, using face-to-face semi-structured interviews.

Participant recruitment

RT from the 12 radiation oncology departments in the Republic of Ireland were invited to participate. They had to be working in direct patient care in Radiation Therapy in Ireland for longer than two years. Managers in each department were contacted and asked to nominate a member of clerical staff to liaise with the researchers in distributing study details to eligible staff. Following

this, timeframes for obtaining informed consent and conducting interviews were arranged with the volunteer RT. Interviews were conducted face-to-face by researcher, FQ, who travelled to each site to interview participants in person.

Data Collection and procedure

Ethical approval for this study was obtained from Trinity College Dublin. An interview schedule (supplementary material 1) broadly covered how HL is assessed, adjustments made for LHL patients, and barriers to supporting this group. An example of questions included: 'Could you characterise a typical low HL patient?', 'Do you interact with, or do anything differently in your approach with low literacy patients?', and 'Do you feel there are barriers or obstacles to helping this type of patient?' This schedule was adapted from the Australian study mentioned previously [14]. Modifications included changes to match local terminology such as "first day chat". Questions seeking participant views on screening for HL level, informed consent, and recording of information sessions were also added. All participants provided written consent, interviews were audio-recorded and transcribed verbatim.

Analysis:

Data were analysed thematically using the Framework method [17,18] allowing identification of commonalities and differences within the data, to draw descriptive and explanatory conclusions centred around themes. Author, FQ led the data analysis, and 3 authors (AC, SS, HD) independently coded 50% of the transcripts, then discussed the issues identified in the data and any discrepancies in coding. In line with recommendations from Ritchie and Spencer *et al.*, [18] the following five steps were taken to analyse data using NVivo Version 10 software:

1. Familiarisation with the data by reading transcripts and identifying themes
2. Developing a coding framework: a framework of themes and subthemes was created and refined. Several iterations of the framework were developed.
3. Indexing: the Framework was applied to the transcripts.
4. Charting: the data were synthesised within a set of thematic matrix charts, where each participant was assigned a row and each subtheme a column.
5. Mapping: similarities and differences of participants' experiences were identified and discussed.

Results

From approximately 200 radiation therapists working in Ireland at the time of the study, 16 RTs consented and participated. Representative of the predominantly female RT profession in Ireland, all were female, with ages ranging from 22 to 54 years. Ten were working six years or less, and six participants worked between seven and 25 years. Participants worked in a range of areas including CT, treatment units, and "information and support" – an RT role dedicated to patient information. Four key themes were identified within the data:

1. Strategies used to identify patients' HL
2. Perceived effect of low HL
3. Obstacles faced when addressing low HL
4. Recommendations to support lower HL groups

1. Strategies used to identify patients' health literacy

Most RTs reported being unfamiliar with the concept of HL, but described the functional element with no mention of the communicative and critical aspects (Table 1). RTs used a range of visual, verbal, and non-verbal cues to identify LHL patients. This subjective identification occurred throughout the patient's treatment. Verbal cues included language used by patients, question asking, and content of questions. Other strategies for identification included non-verbal and visual cues such as body language, demeanour, and ability to carry out instructions.

"It could be the language they use, you might find people refer to their 'radium treatment' or something, usually it'd be something like that that would make you cop on." (P6, 2 years' experience)

Characteristics commonly associated with LHL patients included low education levels, lower socioeconomic and non-professional groups, and over-use of drugs and/or alcohol.

"If they're from a poor socioeconomic background you can kind of gauge that their health literacy might not be as good as someone else." (P20, 4 years' experience)

Some RTs identified difficulties recognising patients with LHL due to a number of factors including limited time spent with patients, patients not speaking or volunteering information, and RTs' lack of awareness of the prevalence of LHL (Table 2).

Participants were more likely to consider HL issues in patients with limited English, or older age.

"The older age group, more rural, less likely to have gone to secondary school" (P16, 14 years' experience)

Other participants questioned whether lack of understanding was due to LHL or other factors such as shock of diagnosis, addictions, anxiety, or cognitive impairment.

All agreed that communicating within the multi-disciplinary team about patients with LHL could be improved, and there is no formal process of reporting LHL patients. Participants acknowledged the importance of alerting team members to ensure a consistency of care, but there was a reluctance to highlight LHL in patient notes due to concerns patients may be offended if seen. RTs indicated concerns about the subjectivity of LHL label, and were reluctant to identify a patient as LHL.

2. Perceived effect of low health literacy

RTs described patients with perceived LHL as preferring a paternalistic approach, wanting their doctor to make their treatment decisions (Table 3). Some participants felt the autonomy of LHL patients was less encouraged than Higher Health Literacy (HHL) patients. Participants felt this was an injustice, although, most acknowledged it could be in the patient's best interests.

Patients with LHL were considered less able to manage their self-care and treatment side effects. Some RTs felt this was due to the initial patient education, whilst others felt it related to the patient's general level of self-care. RTs also reported patients with LHL had difficulty following instructions on side effect management and tended not to mention adverse side-effects. In patients with prostate cancer, low compliance with bladder filling advice was reported by more than half of the participants.

Participants reported providing more complex and nuanced information to those patients they perceived to have HHL levels. Similar amounts of time were spent with both groups, but content of interactions differed. Challenges with HHL patients included their asking unnecessary questions, second-guessing the RT, and increased anxiety due to information overload.

Most participants used both verbal and written resources to relay important information. Regardless of the patient's HL level, verbal information was preferred, with written information provided as a reference. Similarly, irrespective of the HL level, statistics were not used to convey risk information. Information resources provided were deemed suitable for most patients, however, the need for updated information was highlighted.

Participants reported a number of methods for checking understanding, such as asking the patient what they had understood and to summarise the information in their own words. Observing patient compliance, side-effects, and the content of subsequent questions were also techniques used to gauge understanding.

A number of strategies were used to optimise recall and comprehension. These included spending more time with the patient, constant repetition of side-effect management, asking a family member to be present, encouraging question-asking, and drip-feeding information on a 'need to know basis'.

The consent process was an emotive issue for many participants who questioned the efficacy of the process. They reported feeling uncertain about a patient's ability to consent to radiation therapy if they had LHL.

3. Obstacles faced when addressing low health literacy

RTs consistently described the treatment process as a 'conveyer belt' and felt they had insufficient time for patients. Other barriers included: the impact on workflow, the inability to consistently monitor patients, compliance, language, RTs' communication skills, and lack of family support for patients (Table 4).

To optimise communication, participants reported using simplified explanations, analogies, and visual aids. RTs felt designated staff and allocated times for the first day chat would mitigate the impact of reduced resources on LHL patients.

4. Recommendations for improving the management of LHL patients

Participants felt the low levels of awareness of the prevalence and impact of LHL needed to be addressed to improve the care of this population. Education at both an undergraduate and continuous professional development level was suggested (Table 4).

"More awareness. More education, staff education ... a reminder to people once a year to say to keep an eye on the ones that aren't as up to speed" (P19, 25 years' experience)

An increase in the use of visual aids was thought to enhance understanding for the first day chat and in patient waiting areas. The issue of screening received a mixed response, with some participants feeling it could be beneficial, while others felt it could stigmatise LHL patients.

"... if it was highlighted that a patient was struggling to understand the treatment and the impact on their disease then I think it would flag it to health care professionals down the line so they would be able to prepare and give extra time for the patient." (P12, 5.5 years' experience)

"I don't know, again, are you putting more shame on them?" (P3, 17 years' experience)

Discussion

This study details RTs in Ireland's knowledge and awareness of HL and the strategies used to enhance the care and support of patients with LHL adding to the limited studies of HL in radiation oncology by building on a previous Australian study. Similar results to the Australian study emerged with, our results also indicating RTs make subjective, intuitive judgements of patients' HL level at initial interaction and throughout their treatment, and use numerous methods to identify patient HL level. Adding to the Australian results, we identified acceptance of consultation recording as an intervention for consideration, current issues with LHL and consent, and concern with future screening for HL.

Initially participants did not appear familiar with the concept of HL. However, when probed for an explanation, most proffered a definition of functional HL (Table 1). As interviews progressed, it became apparent that although participants did not include the communicative or critical aspects of HL [5] in a formal definition, these were considered. Similar to the Australian study, participants were more likely to consider HL of elderly patients or those not fluent in English[19]. However, consideration must also be given to those with high general literacy as some may still have LHL. In developed countries with compulsory education, such as Ireland, it is thought there may be a large 'hidden population' of people with HL difficulties.[19] These patients are difficult to identify as some are unaware of their LHL status [20] whilst others are ashamed and actively hiding their deficit [29]. Participants spoke of consistently assessing patient understanding which may enable them to identify this 'hidden population,' albeit towards the end of a patient's treatment course.

Low education and low socioeconomic status were the most frequently described characteristics associated with LHL. These factors contribute not only to a LHL status [11, 22], but also low screening attendance [23] and later presentation [24]. Thus, it follows that LHL patients are shown to have poorer outcomes [25]. Interestingly, participants reported, although they changed how information was delivered, they did not change content when speaking to LHL patients, as they felt it was standard and vital information. The literature suggests doctors are inclined to provide less information to patients with limited English and those from low socioeconomic groups [26, 27]. In contrast to HHL patients who were perceived as more informed, and demanding, participants noted patients with LHL were more inclined to abstain from decision making and trust their health care practitioner implicitly. This is in line with the literature [28, 29] which suggests patients with LHL rely more on doctor recommendations, and do not seek information elsewhere.

Building on the Australian research, the issue of poor patient understanding was highlighted when discussing informed consent. In the radiotherapy setting in Ireland, consent is obtained by the Radiation Oncologist. Participants felt patient understanding depended on the oncologist's communication skills and it was sometimes questionable whether the patient understood what they were consenting to. This ambiguity over consent was prevalent in most interviews, warranting further study.

Participants identified a number of challenges associated with LHL patients, including increased patient confusion, interference of family members, increased time demands, and lack of awareness of available services. Participants appreciated that patients who have difficulty understanding information, may also have difficulty in communicating about their health, meaning side-effects experienced may not be raised. In line with other findings, participants described drip-feeding information on a 'need to know' basis so as not to overwhelm patients [30]. New radiotherapy patients want as much information as possible; however, the delivery of this information must be tailored to their background, understanding, and anxiety [14]. In the case of LHL patients, RTs appeared to naturally tailor their communication. The approach taken by the majority of participants was to assume most patients had a limited understanding and to start their communication at a basic level. This technique is described by DeWalt *et al.*, as 'health literacy universal precautions' [31].

Interestingly, although identifying lower socioeconomic status and poor education as important factors associated with LHL, many participants considered prostate cancer patients as the subset with LHL. Participants identified significant issues with understanding of the bladder filling advice given as treatment preparation in this group. Given the visible representation of poor understanding on scanning images, this assumption is understandable. However, inability to independently verify adherence to advice in other subsets of patients may mean attempts to minimise treatment side effects are failing and some patients' needs are being overlooked.

Participants described a number of barriers hindering their ability to help this population. As has been previously discussed, identification, followed by lack of time and resources to assist and support them. Participants noted the importance of holding information sessions in a private space. Participants described techniques to effectively convey information in line with recommendations including using simple language, avoiding medical terminology, using visual aids and analogies, and encouraging patients to ask questions[32]. Recording these information sessions was suggested and most participants were in favour of this intervention, once approved by the hospital.

Although not part of the previous Australian study, the merits of screening all patients for LHL was discussed. Screening patients would allow identification and matching of healthcare materials and services to patients' HL skills. RTs had a mixed reaction towards screening with some questioning the proficiency of screening tools and others feeling it would increase patient shame. There are a number of screening tools available [33] –but as these tools have not been tested in an oncology clinical environment, further research into the usefulness of regular screening is required before implementing it in practice.

The connection between screening, shame, and LHL has been identified previously [34]. Shame inhibits patients from admitting difficulties with reading and writing, seeking additional help to complete medical forms, and asking questions [21]. It was interesting to note that when participants in this study were asked if they felt there was a shame associated with LHL, most felt there was not. However when screening, or highlighting the issue of LHL in a patient's notes were discussed, participants were reluctant to support this due to concern for potential shame felt by patients. This area could be explored further to highlight the issue of shame related to HL.

Suggestions for improving the management of this population included increasing the awareness of the prevalence of LHL and its impact on patient outcomes, as well as communication training for trainees and health professionals. Most participants were not aware of any education initiatives regarding HL in their hospital. Few participants had covered health literacy in their training. This is consistent with existing literature on awareness of HL with Macabasco *et al.* reporting that 80% of respondents had not heard of the concept of HL [35]. Similarly, a large proportion of their participants had no formal training on this topic. Communication skills training can help address the lack of awareness and equip health care professionals with skills necessary to effectively support and care for this patient group [36]. Although further evidence of feasibility and benefits of training is needed, the undergraduate programme for Radiation Therapist's in Ireland has been updated to include lectures on HL, and wider dissemination to the Radiation Oncology professional community has occurred via presentations at national conferences. Studies exploring interventions to enhance communication skills in RTs [37] or providing tools to support communication with patients in radiation oncology have shown promising results [38], but further effectiveness and implementation research is needed to bring these into standard clinical practice.

This study had some limitations. Firstly, the self-selection of participants, with volunteers likely to have an interest in the area. However, given the low awareness of the concept of HL, this did not seem to be the case. Secondly, although representative of the largely female dominated profession in Ireland, these results may not be applicable to male RTs. Thirdly, as this qualitative study includes interviews only with RTs, it is not possible to explore the implications of these data in the context of the multidisciplinary radiation therapy team. Lastly, as we relied on self-reported accounts rather than investigating what RTs say in consultations, this study may have a social desirability response bias, where RT's interactions with patients may be different to their account of these interactions.

Conclusion

This study has demonstrated some knowledge and awareness of HL amongst RTs working in Ireland. However awareness of the different types of HL, its prevalence, and the impact of LHL was lacking. Participants volunteered a number of strategies to improve this situation, with staff training and education a key suggestion. This solution could save time, improve patients' treatment experience and RTs' effectiveness in their interactions.

The four key themes complement the findings of the Australian research. However, further studies with other radiation oncology professionals will provide a wider overview of the knowledge and awareness of HL in the Irish Healthcare system. The current data highlights the importance of further study around understanding and consent in this population, in particular in light of advances in personalised and individualised approaches to care in radiation oncology.

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Table 2 - Strategies used to identify patients' health literacy

<i>2.1 RT interpretation of Health Literacy</i>	<p>I'd say in general just patients' knowledge of their treatment, their healthcare and what it means. (P6)</p> <p>It's just how much information a patient understands, of the stuff that's given to them. (P9)</p>
<i>2.2 Visual/Verbal/Non-Verbal cues used to identify patients</i>	<p>It could be the language they use, you might find people refer to their 'radium treatment' or something, usually it'd be something like that that would make you cop on. (P6)</p> <p>I think just on the day when you meet a patient you can just tell from their body language and just their whole demeanour whether they are understanding or not (P3).</p>
<i>2.3 Characteristics of low health literacy patients</i>	<p>If they're from a poor socioeconomic background you can kind of gauge that their health literacy might not be as good as someone else. (P20)</p> <p>Sometimes maybe with social problems so they might have a background of alcoholism or previous involvement with social workers. (P8)</p>
<i>2.4 Identifying low health literacy patients</i>	<p>If you're explaining something to someone, you'll get people who just agree to everything. You're getting the date of birth, getting the address and you ask them have they ever had a CT scan before and they'll just kind of nod and agree with everything you say. (P5)</p> <p>I just feel it would be very difficult to pick up that a patient didn't know what was happening.....How anyone would pick that up without the patient saying they didn't really understand. (P17)</p>
<i>2.5 Consideration of elderly patients and patients with limited English</i>	<p>These patients (foreign nationals) can't even say their date of birth and you'd wonder how can they ever communicate any problems. (P9)</p> <p>But at the same time it depends on the age group of patients you're talking about. The older age group, more rural, less likely to have gone to school, to secondary school, so they might only have done literacy until ten or twelve and then they've worked on a farm. (P16)</p>
<i>2.6 Other factors affecting understanding</i>	<p>Patients who are not actively helping themselves get through the treatment so for an alcoholic, I would think they have trouble understanding the impact this would have on their disease and treatment. (P17)</p> <p>The shock is so intense, they just sign the papers, yes I want to go ahead, and they don't know the consequences. Even if they're told, they just forget. (P14)</p> <p>Sometimes it's not down to lack of knowledge, they just don't want the knowledge as well (P16).</p>
<i>2.7 Improvement needed in communication about patients' health literacy</i>	<p>Definitely. Because it means that people are going to need to reiterate advice, to be more vigilant in watching them. Because he says he has had water to drink – check how much he has had. Yeah I'd definitely flag it. (P8)</p>

<i>within the multidisciplinary team</i>	I suppose yeah, because when they come to CT they've already been up in out-patients where they're being consented so I suppose they're the first port of call. But it has never been relayed to us that a patient is confused, unless it's disease related, rather than the patient just not having a good understanding of it. (P20)
<i>2.8 Reluctance to write in patient notes</i>	<p>I suppose everyone is very aware of the freedom of information for patients. And if a patient requested their notes and saw this written down, and you know, have you got definite proof of it? That's why I would be cautious of writing it. (P15)</p> <p>I suppose I would just be conscious that this is something that, if the patient in the future wants to pull their medical information, it's all in there. And also, unless I'm told by a medical person or the patient themselves that they have low health literacy, who am I to judge what level they have or don't have? (P16)</p>

Table 3 *Perceived effect of low health literacy*

<i>3.1 Paternalistic attitude of patients</i>	<p>"Most of them don't want to know anything. It's 'I need treatment, I'll go for it.' They don't understand, during the treatment they're saying 'I have diarrhoea, what's going on?' because they didn't understand at the beginning." (P14)</p> <p>They say 'the Doctor knows best so I'll do what the Doctor says.' (P20)</p>
<i>3.2 Family interference and decreased patient autonomy</i>	<p>I think quite often what happens is that relations come with them and there's almost more discussion with the relations and they almost interpret (to the patient). In particular if they're (family) a younger generation. (P19)</p> <p>I'm sure there would be a difference. I'm sure that if you identified a low health literacy patient you wouldn't give them the option to take a more decisive role in their treatment, but there shouldn't be (a difference), that's not right. (P17)</p>
<i>3.3 Patient's ability to manage self-care and side effects</i>	<p>...So I think if you explain it well, they should be able to do it. But I suppose if they don't understand they wouldn't be able to do it as well, but I think that's where our responsibility comes in (P20).</p> <p>I would say more often than not their self-care is fairly poor to begin with ... But I suppose often they don't take care of themselves very well so they don't manage their treatment side effects well either. (P3)</p> <p>They may not follow instructions so their side effects could end up quite bad. Or they may not understand how severe the side effects may become. They may not understand that so they may go too far before you can prevent that. (P9)</p>
<i>3.4 Meeting the needs of different health literacy groups</i>	<p>I would probably end up spending, maybe slightly less but probably similar amount of time because you're just focussing your information on different things. You're giving different information, well not different information but more extensive information, you don't need to go repeating yourself constantly. (P16)</p> <p>It can be really challenging if somebody's got a lot of questions, especially if they're kind of irrelevant or vague. (P12)</p>

<i>3.5 Best methods of information delivery</i>	<p>I think it has to be a combination of written and verbal. I think if you just give somebody a lot of written information they tend not to read it. Again if you give them a lot of verbal information they won't take it all in and they won't remember. So I think it has to be a combination of both. (P12) I think verbal. Just having a discussion with somebody, with written information (to follow). But verbal information is essential and having it one-to-one with the patient is essential. (P18)</p>
<i>3.6 Assessing patient understanding</i>	<p>I suppose just on a daily basis ask 'do you have any questions? Are you happy with the side effects? Are you putting on any cream?' Just making sure they're following the skin care protocol or taking the meds that they've been given. (P12)</p> <p>I almost get them to repeat in their own words, what we've gone through, the main points. Or like that if I'm showing a patient how to use our scanning equipment (used for checking in), I'll show them and then I'll get them to do it. (P15)</p> <p>I think I'd probably try to be more subtle. Sometimes you might visually see it. Like a patient's skin for example.....Or if you see that the area is not being looked after....then I suppose you could probably ask. (P4)</p>
<i>3.7 Strategies to enhance recall and understanding</i>	<p>I'd probably give them longer in the information talks. If they needed another appointment to be booked I would probably do that as well. (P16)</p> <p>I'd reiterate again the most important points for that specific site. Because they hear so much, I would just make sure, remind them to be well hydrated. (P8)</p> <p>I would encourage the patient to ask questions to any of the staff if they did have further questions. (P12)</p>
<i>3.8 Consent</i>	<p>If they didn't have a good understanding of the treatment they wouldn't know what they've consented to. They might not know the side effects until after they've started. (P6)</p> <p>Yes, I would be and that's something I have been concerned about over the years – does the patient understand? (P19)</p> <p>The consent process in general is a funny thing. It's a good thing because I think it's forcing medics to sit down in a more structured way. But that's an ideal scenario. If the consent is done in an ideal scenario as it's supposed to be done then that's fine.....It's not always done as it should be. (P19)</p>

Table 4 Obstacles and recommendations to support lower health literacy groups

Obstacles	
<i>4.1 Time and Resources</i>	<p>Our system is so rigid that it's not about allowing extra time for anybody. It's about reducing time for everybody. (P16)</p> <p>I think working within our time constraints currently hinders our ability to treat any of our patients with the 100% care that we should be giving them. (P17)</p>
<i>4.2 Ability to tailor communication</i>	<p>You'd simplify it, and you'd give one instruction at a time, wouldn't bombard them with information. Simplify it and try to make sure they've understood it. (P18)</p> <p>I try to use analogies with the prostate patients, like the bladder – they always ask why do I have to drink the water. If they're complaining and giving out about the water, I say the bladder is like a balloon, and if it's full, and we're delivering the treatment at it, and I'd be using my hand signals, there's less of it getting treated, if it's empty, there's more of it. So I think visual things are more useful. (P4)</p>
<i>4.3 Overcoming Obstacles</i>	<p>We've recently started here that the floating* RTs are doing the first day chats. Because we noticed ourselves that patients were being chatted to as they were walking down the corridor into the room, which isn't ideal but it happens because of the time and resources and the way we work shifts. (P4)</p> <p>Now we have a little more staff and some of the floaters*, they would go down on the first day and take the patient into a smaller room and maybe spend 20 or 30 minutes with them. (P4)</p>
Recommendations	
<i>4.4 Increase awareness amongst staff</i>	<p>More awareness. More education, staff education. Just an awareness. Raising awareness and just a reminder to people once a year to say to keep an eye on the ones that aren't as up to speed. (P19)</p> <p>Well first of all we've to be aware of them, we have to be educated ourselves. And then I suppose we have to discuss how we could make the communication easier, which mode of communication is best. (P17)</p> <p>Obviously if staff were trained and had more knowledge on how to interact with people with low health literacy. (P20)</p>
<i>4.5 Increased use of visual aids to improve delivery of treatment</i>	<p>DVDs, we have that but I think it's only for curative patients, to show them what's going on and what side effects they might have. (P14)</p> <p>A flipchart explaining what radiotherapy would be like every day, that could be an improvement for them. Even to give them one at CT, a small little flipchart with some images of the scanner or machine and what would happen every day when we leave the room. (P5)</p> <p>A video loop or something that would enable our patients to gain more of the information that they need in relation to their health. (P15)</p>

4.5 Screening

Yeah, I think if patients were highlighted, if it was highlighted that a patient was struggling to understand the treatment and the impact on their disease then I think it would flag it to health care professionals down the line so they would be able to prepare and give extra time for the patient. (P12)

I think it's a hard one to call and I think you're also, you're defining them from the start of treatment. You're giving them a test. (P19)

I don't know, again, are you putting more shame on them? (P3)

*floating/floater = additional RT- not assigned to a specific unit but provide cover for those on holidays or sick leave



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Conflict of Interest

Conflict of Interests: the authors declare that they have no conflict of interest.

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